

Evaluating Ethics Committees: A View from the Outside

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DURING THE LAST DECADE, THERE HAS BEEN REMARKABLE growth in the number of health care institutions with ethics committees. These are multidisciplinary committees established to address ethical dilemmas in patient care. The committees often deal with issues regarding the withholding or withdrawal of life-sustaining treatment from patients who lack decision-making capacity (Cranford and Doudera 1984). Although the number of hospitals with such committees was estimated to be less than 100 in the early 1980s (Youngner et al. 1984), by 1985, according to a survey by the American Hospital Association (1985), more than 60 percent of American hospitals had their own ethics committee. There are no more recent national estimates of the number of hospitals that have established these committees, but there is reason to believe the numbers have grown in the last eight years.

The motivation for establishing these committees has been mainly internal: nurses, social workers, and physicians initiated the committees as a better way to deal with cases that involved the withholding or withdrawal of life-sustaining treatment. However, a series of external events undoubtedly influenced their formation as well. Among them was the 1976 New Jersey court case of Karen Ann Quinlan,¹ a young woman

¹ *In re Quinlan*, 355 A.2d 647, cert. denied 429 U.S. 922 (N.J. 1976).

who had been in a persistent vegetative state for several years. At issue in the case was whether Karen's father had the legal right to authorize her removal from a ventilator. In its opinion, the New Jersey Supreme Court quoted an article by Dr. Karen Teel, which suggested that the way to improve medical decision making was for each hospital to establish an "ethics committee composed of physicians, social workers, attorneys, and theologians . . . which [would serve] to review the individual circumstances of ethical dilemma[s] and which [would provide] much in the way of assistance and safeguards for patients and their medical caretakers."²

The value of ethics committees received increased attention in 1983, when the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published its report, *Deciding to Forego Life Sustaining Medical Treatment*. The commission concluded that, in order to protect the interests of patients who lack decision-making capacity and to ensure their well-being and self-determination, health care institutions "should explore and evaluate . . . various administrative arrangements for review and consultation, such as 'ethics committees' particularly for decisions that have life or death consequences. . . ." (1983, 5).

A third external motivating factor for the establishment of these committees was the promulgation in 1985 by the U.S. Department of Health and Human Services of the "Baby Doe" regulations.³ These regulations strongly encouraged, but did not mandate, that hospitals caring for newborns establish infant care review committees to review cases where the withholding of life-sustaining treatment of a newborn was being considered.

Since the *Quinlan* case, a handful of court cases have mentioned the positive role that an ethics committee can play in dealing with difficult medical treatment issues. Probably the strongest endorsement of the committees came from the Supreme Court of Minnesota in the case of *In re Torres*.⁴ In that case, the court stated that an affirmation by an ethics committee of a family's decision to withdraw life support from a patient in a persistent vegetative state would eliminate the need for judicial ap-

² Id. at 49, 355 A.2d at 668 (quoting Teel, *The Physician's Dilemma: A Doctor's View: What the Law Should Be*, 27 Baylor L. Rev. 6, 9 (1975).

³ 45 C.F.R. § 1340.15 (1991).

⁴ *In re Torres*, 357 N.W. 2d 332 (Minn. 1984).

proval. A similar endorsement came from the New Jersey Supreme Court in the case of *Nancy Jobes*.⁵ The court spoke favorably of the role of ethics committees in assisting family members and health care providers to make decisions about the withholding or withdrawal of life-sustaining treatment from incapacitated patients.

This wave of enthusiasm for ethics committees also resulted in one state (Maryland) mandating their establishment by statute,⁶ another state (New Jersey) mandating the establishment of either an ethics committee or a prognosis committee by regulation,⁷ a third state (New York) considering making them mandatory (New York State Task Force on Life and the Law 1992), two states (Maryland and Hawaii)⁸ immunizing them from liability, and the introduction of a bill into Congress⁹ that would have required every hospital in the country to establish such a committee. More recently, the Joint Commission on the Accreditation of Health Care Organizations (JCAHO) has recommended in its accreditation guidelines that hospitals establish a mechanism within the institution to resolve ethical dilemmas in patient care.

The fact that some legislatures and courts, and a powerful body like JCAHO, appear to have wholeheartedly embraced these committees is truly surprising, given the paucity of data on their impact or effectiveness. These efforts to mandate or encourage the widespread establishment and use of ethics committees seem to ignore some of their risks. Levine pointed out:

Hospital ethics committees, like any institutional arrangement, can be used for ill as well as for good. They are in essence a procedural mechanism that can aid those faced with difficult ethical decisions; their presence does not guarantee that they will be used constructively or that the most appropriate decision will be made. (1984, 9)

More than a decade ago, Youngner et al. (1984) referred to hospital ethics committees as "poorly defined, unproven entities." Today, ethics committees may be somewhat better defined, but they remain largely

⁵ *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987).

⁶ Maryland Annotated Code. 1990. Health General Article. §§ 19-374.

⁷ New Jersey Department of Health. 1990. Regulation and Administration Code § 8:436-5.1, Licensure Reform Subchapter.

⁸ Hawaii Rev. Stat. §663-1.7 (1988 & Supp. 1990).

⁹ S.1766, 101st Cong., 1st Sess.

unproven. In fact, "it has not yet been shown that [healthcare ethics committees] actually facilitate either the decision-making process or better decisions regarding ethical questions" (Mahowald 1989).

Since 1983, there have been several hundred articles written on ethics committees, but few have set forth a systematic framework for evaluating them, and none has done so from a public policy perspective. My goal in this article is to begin filling that void by imparting a conceptual framework for evaluating ethics committees from a public policy or societal perspective; applying available data to the framework; and pointing out areas where additional empirical research is necessary.

Evaluation Efforts to Date

A number of researchers have collected data that might be used in the evaluation of ethics committees. These studies have generally focused on structural aspects of ethics committees: for example, the number of members on a committee; the composition of the committee by discipline; who has access to the committee; and types of functions that such committees perform (see studies by Youngner et al. 1984; Kushner and Gibson 1984; Nash, Leinbach, and Fought 1989; Minnesota Ethics Committee Network 1990; D'Oronzio, Dunn, and Gregory 1991; Hoffmann 1991; and Schierton 1992). Some, however, have gone another step and looked at user satisfaction or perceptions of potential users. Youngner et al. (1984), for example, assessed patients' attitudes toward hospital ethics committees generally. I surveyed approximately 2,000 physicians, nurses, and social workers at five Maryland hospitals, asking whether they had used their hospital's ethics committee, and if so, whether they had found it helpful to their decision making (Hoffmann 1991). La Puma and coworkers (1988, 1992) examined the satisfaction of physicians who used an ethics consultation service at a university and a community hospital.

With a few notable exceptions, writers have not suggested either normative standards or a systematic framework for evaluating ethics committees. The few who have attempted to formulate generalizable criteria have done so mainly from the perspective of an insider—often an ethics committee member or an institutional administrator. Typically, the discussion has focused on a single committee. For example, Povar (1991) examined the validity of two criteria for success of an ethics committee in

its roles of policy making and case consultation—institutional acceptance and consensus within the ethics committee—and used her own ethics committee experience in applying the criteria. Van Allen et al. (1989) suggested that the yardstick by which ethics committees should be measured is their own mission statement.

Others either have taken a narrow view of what constitutes appropriate measures of success or have not explicitly described the perspective of their evaluation. Fletcher (1989), in suggesting standards for evaluating ethics consultation, focused exclusively on process issues; for example, has the consultant or committee clarified the options, interviewed the appropriate parties, reviewed the patient's chart? Tulskey and Lo (1992) went a bit farther. In critiquing the 1992 study by LaPuma et al., which looked exclusively at physician satisfaction, they suggested that evaluation criteria should include patient and surrogate satisfaction, reactions of nurses and house staff, and objective measures for resolving dilemmas. This last criterion, however, was not defined. Finally, insightful pieces by Lo (1987) and by Griener and Storch (1992) include thoughts about criteria for evaluating ethics committees, but they do not attempt a comprehensive framework for doing so, nor do they state the perspective from which the ethics committees should be evaluated.

The First Stumbling Block: Clarifying the Perspective of Evaluation and the Purpose of Ethics Committees

Any evaluation will be based largely on answering the question, Is the service or entity being evaluated achieving its purpose or goal? Thus, before standards or criteria can be established, the entity's purpose must be defined. The answer to this question, however, will depend on who is being asked and what perspective that person or organization is working from. Groups or organizations that may have an interest in evaluating ethics committees include committee members, patients, health care providers, hospitals, insurance companies, state or federal agencies, judges, and legislators. Each group will view the purpose of these committees differently. Thus, the perspective of any evaluation must be clarified before embarking on such an effort.

In this article, I plan to take the perspective of public policy makers: legislators and government agency personnel, for example. Given that

legislation has been enacted and proposed either to require ethics committees or to encourage their use, and that a handful of courts have mentioned using ethics committees as an alternative to judicial decision making, it seems appropriate to ask, How should public policy makers evaluate them?

Evaluation efforts from a public policy or societal perspective not only may assist policy makers in thinking about mandating ethics committees, but also may help them to decide whether the committees should be authorized to substitute for judicial review or be given immunity from liability, or whether state or federal programs should fund ethics committees or reimburse hospitals for the costs of their consultations. Because these policy questions have been raised and are currently under consideration in some legislatures and courtrooms, legislators, judges, and state and federal agencies should be interested in assessing these committees' overall performance.

This perspective leads to the question, What is the appropriate purpose from which to evaluate ethics committees? Unfortunately, ethics committee purposes have become confused with their functions (Capron 1984). The three basic functions consistently identified as constituting the realm of ethics committee activity are (1) case consultation, (2) policy development, and (3) education.

These functions can be separated from the more fundamental purpose of ethics committees. Although several authors have argued that the primary purpose of ethics committees *should be* protection of patients' interests (President's Commission 1983; Capron 1984; Macklin 1984; Veatch 1984; Pellegrino and Thomasma 1988; Cohen 1989; Wikler 1989), in practice it is not clear that this is, in fact, their purpose. Committees may have other purposes, not related to patient protection, that they do not always openly admit to. For example, they might have a more objective goal of assisting patients, family members; additionally, health care providers do what is "ethically correct" while balancing the interests of the patient, his or her family members, the health care provider, the institution, and any other interested parties. Ackerman (1989) has discussed these two potentially conflicting purposes in his review of the role of the ethics consultant. He states that a difficult question is whether the consultant "should focus upon assessment of the moral interests of the patient or should embrace an impartial analysis of the competing moral interests of other relevant parties." (1989, 42)

Other ethics committee purposes might be to manage risk and protect the interests of the institution, the physician, and other health care providers (Robertson 1984). Finally, their guidelines might include a policy

goal such as ensuring the fair allocation of scarce medical resources within the hospital (*Medical Ethics Advisor* 1990).

Some authors have argued that resource allocation and risk management are inappropriate purposes for ethics committees, not because these goals are unworthy in and of themselves, but because they conflict with the goal of patient protection (Veatch 1984). Wolf (1991), for example, persuasively argues that there are real dangers in what she calls the "double identity" of ethics committees, whereby one minute they are advising caregivers and the next, serving patients. She sees these conflicting roles as especially problematic for patients because they will never know "precisely where they stand" vis-à-vis these committees.

This duality or multiplicity of purposes creates confusion for ethics committees, so that, rather than explicitly setting forth their goals, many leave their purposes unstated or intentionally vague. For example, the ethics committee at Hennipin County Medical Center considered its vagueness a virtue. In response to a survey question by Kushner and Gibson, the committee responded:

We have never formally stated in writing the exact purpose or purposes of our committee but have decided to proceed in an informal manner. This was deliberate on our part because we felt that if we became too formal in our stated procedures, there might be negative repercussions from the physicians and others in our hospital who have a misunderstanding of the function of our committee. We felt that to formalize our objectives might be counterproductive to the work of our committee. (1984, 100)

Such vagueness, however, may lead to problems down the road. Furthermore, it also makes it difficult for ethics committees to evaluate their own performance. Confirming this difficulty, Fletcher argues that evaluation which "aims to judge the merit or worth of [a] program or activity by determining its effects or outcomes" (1989, 173) is not appropriate for ethics committees because it assumes that a clear set of goals and program objectives had been established. He states that "it would be surprising to find a health care institution in which goals and objectives of this activity had been carefully defined from the outset" (173).

Although at the institutional level members of a committee may be confused about its purpose, or may not even have thought about it, from a public policy perspective their purpose must be patient protection. The purpose of safeguarding patients' interests is consistent with the government's history of exercising its *parens patriae* role to protect

the vulnerable. Without a doubt, patient protection motivated the government to mandate or encourage the creation of ethics committees, with particular emphasis on the issue of withholding or withdrawal of life-sustaining treatment for patients who have lost decision-making capacity (Jaffe 1989). The President's Commission envisioned this issue as the primary concern of ethics committees, and it described their duties as ensuring "that the interests of all parties, especially those of the incapacitated person, have been adequately represented [and] to promoting the well-being of incapacitated patients" (1983, 164). Furthermore, public policy norms for resolving cases about treatment of patients are based on following the patient's preferences or doing what is in the patient's best interests. Thus, any effort to evaluate ethics committees from a public policy vantage point must begin from the premise that their goal is to protect the interests of patients.

Laying Out a Comprehensive Framework: Where to Begin?

In evaluating a new program or intervention, policy makers, funding organizations, planners, and administrators typically ask the following questions:

1. Is the program/intervention reaching the appropriate target population?
2. Is it effective?
3. How much does it cost?
4. What are its costs relative to its effectiveness?

These questions, somewhat modified, form the basis for my proposal that ethics committees be evaluated using the criteria of access, quality, and cost effectiveness. I argue that these three criteria should be used to assess each of the three major *functions* performed by ethics committees from the perspective of their purpose.

The Criteria: A Justification

Access

Fost and Cranford have asserted that "the most controversial question confronting an institution considering formation of an ethics committee

is the definition of access and jurisdiction" (1985, 2690). Access is obviously important for the function of case consultation because without it potential users will not utilize the committees. Thus, we need to know whether there are obstacles to the committees' use: Do potential users know about the committees? How are they notified about the committees and gaining access to them? Are the procedures for use uncomplicated? Do potential users understand what the committees do? Do they think the committees worthwhile? Would they use the committees? If not, why not? All of these questions should be asked when evaluating a committee from the perspective of case consultation. However, access may also be important from the perspective of policy development and education. If our goal is to develop policies that are satisfactory to the community at large, we may want to invite "outsiders" to participate in policy development discussions. Similarly, if we want to educate the hospital staff, or those served by the institution, about ethical issues in patient care, we must ensure that all relevant staff, as well as patients and their family members, have access to the committee's educational activities.

Quality

The quality of ethics committees is perhaps the most important evaluative criterion, yet it is probably the most elusive to define and apply. In defining quality, I borrow from the framework proposed by Donabedian (1980). His three components—structure, process, and outcome—have been generally accepted as the starting point for thinking about the evaluation of health care quality.

In the health care setting, structure includes the tools or resources put into the care provided: the physical plant or facility, the individuals who provide the care and their qualifications, and the equipment or hardware utilized. The structure of ethics committees would largely comprise the individuals serving on them: their qualifications and expertise.

Donabedian uses the term "process" to refer to the interaction between the health care provider and the patient: what the provider says, how she arrives at a diagnosis, what tests she administers, what drugs she prescribes, and so forth. In the context of ethics committees, process would include due process issues as well as the exchanges between committee members in the consultations and committee meetings.

In evaluating health care services, outcome generally means the health status of the patient: on some objective scale, did the patient's health improve? Donabedian includes not only the physical and physiological

aspects of health, but also the social and psychological factors. Furthermore, he extends the definition to encompass patient attitudes, that is, some measure of the patient's satisfaction with the care he or she received. Thus, his measure of outcome includes both subjective and objective criteria. In the context of ethics committees, other than criteria based on user satisfaction, it is not clear what the appropriate outcome criteria would be. Is there some yardstick of "ethical rightness" that we can consult?

In assessing the quality of health care provided, Donabedian and other evaluation experts (Jonas 1977) assert that process and outcome are our greatest concern. Although, historically, structure has been the basis for evaluating the quality of health care, academics have criticized this criterion as ineffective and as not clearly leading to good outcomes. Structural indicators alone often cannot be relied upon as adequate measures of good quality care.

There is also considerable debate in the evaluation literature regarding how much relative weight should be given to process versus outcome measures. Process as a basis for evaluation assumes that good process leads to good outcomes, whereas outcome measures assume that good results are directly related to good care. Obviously, there are exceptions to these assumptions. A patient can improve in spite of poor treatment and can deteriorate in spite of the best medical treatment.

I will address the limitations and potential for using each of these approaches—structure, process, and outcome—to assess the quality of ethics committees.

Cost Effectiveness

Some have suggested that we examine the cost effectiveness of ethics committees when we are evaluating them. Others have argued that such a criterion is inappropriate because our concern should be the quality of the committees' ethical deliberations and advice, not their cost, a view that I regard as naive and unrealistic. If we view cost broadly as including the value of time, the cost of using ethics committees will be important to health care providers, patients, and their surrogates. Their budget and personnel costs will also be important to institutions that provide resources to the committee. As Povar states:

Ethics committees often demand substantial time commitments from participants, and to be effective, real financial commitments from ad-

ministrators. It is likely that these people will demand evidence of success, including defensible outcomes, in return for their investments of time and money. (1991, 907)

Similarly, cost effectiveness as a basis for evaluation is likely to be of concern to public policy makers, who may be confronted with proposed legislation that would mandate ethics committees, or who are trying to determine how to allocate scarce federal or state dollars. Although no legislature is currently funding institutional ethics committees, cost effectiveness would be a likely criterion if funding or reimbursement of committee consultations were to be considered by a legislature or by the Health Care Financing Administration under Medicare.

Evaluators will want to know how the costs and achievements of ethics committees compare with alternatives like individual ethics consultants, the hospital legal counsel, the hospital chaplain, a psychologist or counselor, or a court.

Applying the Criteria to a Selected Function

To demonstrate the applicability of the framework, this section of the article applies the proposed criteria to the function of case consultation. To the extent possible, existing data are utilized in the evaluation process. Much of the data for this section is based on the following sources: a study of hospital ethics committees that I conducted in Maryland, the District of Columbia, and Virginia (Hoffmann 1991); the work of the Minnesota Ethics Committee Network (1990); research by D'Oronzio, Dunn, and Gregory (1991) in New Jersey; a study by La Puma et al. (1992) on bioethics consultants in Illinois; and research by Youngner et al. (1984) on patient attitudes toward ethics committees at a Cleveland Hospital.

Although I will try to adhere to the proposed framework, its application raises fundamental questions about ethics committees and highlights areas that require more data and empirical work. The framework also reveals the limitations and difficulties of using some of the identified criteria.

Access

If a committee's goal is to protect the interests of patients, the committee must ensure that patients or their surrogates have access to the com-

mittee. Although my study of hospital ethics committees in Maryland, the District of Columbia, and Virginia (Hoffmann 1991) showed that patients and their family members are infrequent users of the committees, the study did not assess whether patients or their families knew about the committees or their function. However, the study by Youngner et al. (1984) of patient attitudes toward ethics committees at one hospital found that only 8 percent of the patients questioned knew that the hospital had an ethics committee. Of those 8 percent, none correctly perceived the committee's actual function. Although ten years have passed since that study was conducted, it is unlikely that the level of patient awareness of these committees has changed perceptibly. Most hospitals have not established any formal mechanism for notifying patients and family members of their existence (Nash, Leinbach, and Fought 1989). Furthermore, the general media have not carried much information about them.

Access by patients and their family members to ethics committees depends in large part on their health care providers' awareness of the committees and whether they elect to inform patients and their families about them. The Maryland Study (Hoffmann 1991) addressed this question directly. Health care providers (attending physicians, residents, nurses, and social workers) at five Maryland hospitals with long-standing committees were asked whether their hospital had an ethics committee. Approximately 35 percent of respondents said that they did not know whether their hospital had such a committee. Attending physicians were somewhat *less* likely to know than the other groups surveyed. Because health care providers exert so much control over their patients and their access to ethics committees, it is important that both health care providers and patients be informed about the existence of the committees and their ability to utilize them.

An evaluation of access must also consider whether there are any obstacles to use of the committees by patients and their family members. For example: Do patients or family members understand the role of the committees? Are they intimidated by the thought of using a committee for such personal matters as withdrawal of life support? A thorough evaluation would solicit this information from hospital patients and their families.

Another question that should be asked with respect to access is whether the committees are acting to protect patients when patients cannot speak for themselves and either have no family members or have

family members who will not request help from the committee. Lo (1987) points out that "people who need the most help in expressing their preferences or interests may be the least likely to request a meeting. They may be cognitively impaired or unable to navigate the medical system or there may be cultural, language or educational barriers" (47).

Ethics committees have generally been reactive in their case review. If they are to protect patients, they must take a more proactive stance in some cases. Certainly, patient representatives and ombudsmen should be informed about the committees and should have access to them, which means that they must be told of the committees' existence and purpose and apprised of their right to utilize them when they believe patients' interests are not being served.

Quality

Structure. In assessing the quality of case consultation services provided by an ethics committee from the perspective of protecting the patient's interests, structurally we will want to ensure that the committee includes members who will serve the interests of patients and their representatives. Most committees are heavily dominated by health care professionals (Minnesota Ethics Committee Network 1990; Hoffmann 1991; D'Oronzio, Dunn, and Gregory 1991), and it is questionable whether they will adhere consistently to the goal of safeguarding the patient's interests. Although these individuals will often put the patient's interests foremost, they also may carry to the table the biases of the medical profession, and they may assess the risks and benefits associated with a particular treatment differently than a patient would. They may also feel an obligation to protect their fellow professionals and the hospital from liability, or perhaps they may believe that they have a duty to contain costs or to preserve limited health care resources. These valid objectives may be at odds, however, with the patient's wishes or best interests. Furthermore, health care providers may not share the values of the patients under discussion. If the primary goal of ethics committees is to protect patients' interests, a strong argument can be made that committees should be more heterogeneous and should include representatives of the community such as other patients and individuals who are likely to share the patients' values. This might mean modifying the committee based on the specific patient seeking assistance. For example, a representative of the religious denomination of an individual with strong religious beliefs

might be brought in to consult with the committee. To make patients and their surrogates feel welcome, committees could include individuals with a counseling background, like social workers, psychiatrists, clergy, or clinical psychologists, who are experienced in dealing with crises and grieving. An evaluation should ask whether committees include individuals who have these characteristics.

Although, along with other authors, I have espoused the criterion of heterogeneity in ethics committee composition, admittedly more work needs to be done to examine how this structural criterion is related to process and outcomes in ethics committee case consultation. Schierton (1992) has made some headway here. In a study of 137 hospital ethics committees, she found that a multidisciplinary committee does not necessarily ensure committee "success." However, her measure of success—the number of interventions undertaken by the committees in each functional area—is not necessarily consistent with my espoused goal for ethics committees: protection of patient interests.

Process

At least three models of process might be appropriate for ethics committee consultations. The first two, described at length by Wolf (1991), are (1) an adjudicatory model, in which the committee hears from the relevant parties and makes a recommendation, much like a judge or arbitrator, and (2) a consultation model, which is analogous to the medical consultation practice of medical staff consulting with other medical professionals about the treatment of a specific patient. In the consultation model, a patient may not be notified of the consult. A third model, mediation, may be appropriate in some cases, especially where dispute resolution is required. As described by Gibson and West (1991), the committee in this model would act as a facilitator or mediator, convening all the relevant parties and assisting them to arrive at a mutually agreeable solution.

When the goal of the committees is patient protection, the consultation model is problematic. Wolf (1991) has attacked this model as dangerous for patients, as it affords them no notice or other due process protections.

For incompetent patients, the adjudicatory model, in most cases, should provide the greatest patient protection. In establishing standards

for the adjudicatory model, it is important to distinguish between the type of procedure associated with due process, which is generally external to the deliberative process of a decision-making body (i.e., notice and an opportunity to be heard), and the internal workings of the body (i.e., how it arrives at a decision). Wolf (1991) argues convincingly that if we are concerned with protecting patients' interests, ethics committees must incorporate elements of procedural due process in their operations. She specifically advocates that committees notify a patient or surrogate about any case consultation involving that patient and state the process the committee will use and how the patient or surrogate may participate in it; that the patient or surrogate be permitted to bring to the consultation anyone he or she wishes, including a physician, lawyer, clergy, or ethicist; that the patient or surrogate be given an opportunity to participate in the consultation and to challenge statements made by committee members and health care providers; and that the patient receive both a written explanation of the recommendation of the committee and an opportunity to discuss the recommendation with committee members.

Wolf persuasively argues that this type of procedure is needed. Although it is debatable whether full-blown due process protections are necessary in each case, as there is a valid argument that these procedures will make ethics committee case reviews more adversarial than they need to be, at a minimum relevant parties should be given notice, an opportunity to be heard, and an explanation of the recommendation of the committee, if one is made. Yet Wolf points out that ethics committees are a "due process wasteland" — that "there is no indication that committees regularly offer patients any of [these basic protections]" (831).

Any systematic evaluation of ethics committees should seek to determine to what extent these procedural due process protections are provided by ethics committees. Although many of these protections are intrinsically valid, it would also be helpful to know to what extent they actually make a difference in patient outcomes and user satisfaction.

As to what constitutes appropriate deliberative, internal procedures, it seems that there is little consensus. For example, does it matter whether the committee discussed, or did not discuss, formal ethical concepts? whether they discussed the relevant law? whether they used a process of consensus or majority vote to reach a recommendation? Van Allen et al. (1989) have asserted that we should consider "meaningful dialogue" as one measure of the effectiveness of an ethics committee, but they do not offer a definition of meaningful dialogue. Although it is as difficult to

arrive at objective criteria for evaluating the internal process of an ethics committee, I believe some specific measures should be considered:

1. Did all relevant parties—health care providers, patient, family—have an opportunity to speak?
2. Did members of the *committee* participate freely in the deliberations, or were the discussions dominated by a few individuals?
3. Did anyone try to gather facts about the patient's wishes? If the goal of the committee is patient protection, evaluators will want to ask whether anyone attempted to determine the patient's preferences: Were any documents that the patient prepared reviewed by the committee? Were family members or friends who knew the patient interviewed? If no family members or friends were available, were there interviews with health care providers who knew the patient's preferences?
4. If there was no, or insufficient, information available about the patient's preferences, was any effort made to determine the best interests of the patient? How was this determined? Were the factors considered consistent with the literature on this issue? Was each member of the committee asked to express an opinion about the patient's best interest? Were committee members whose values were similar to the patient heard from?
5. Did the committee have the relevant medical and legal information as well as the ethical input it needed? This question raises another one: Who is to decide what is relevant? Such evaluation arguably requires that an independent group with expertise in these areas evaluate the committee's deliberations, either by unobtrusively sitting in on committee deliberations, by observing video- or audiotapes, or by reviewing notes, if any, of the consultations. Hospitals have resorted to peer review to evaluate the care given by health care providers. A similar concept could be applied to ethics committees. A specially trained, interdisciplinary team consisting of a bioethicist, a physician, and an attorney could evaluate this aspect of the committee's process.
6. Did the committee use a process designed to reach consensus and vote on the appropriate outcome, or did it simply leave the recommendation up to the chair or a smaller group? The Maryland Study (Hoffmann 1991) found that most committees attempt to reach a consensus. I am aware of a few committees that make no effort to

seek a consensus, but instead just outline, from an ethical perspective, the various options open to the parties and their pros and cons. Moreno (1990) and Gregory (1990) argue that the value of committee consensus is that it is a representation of the "social intelligence" or "common wisdom of the committee," reflecting the "moral climate and direction of the institution and perhaps of the community at large."

These criteria are appropriate if a committee has adopted an adjudicatory model for case consultation. Regarding the third model, mediation, described by Gibson and West (1991), if the purpose of ethics committees is to protect patient interests, there may be good reason to be skeptical about it as a process for some ethics committee cases. Mediation, for example, may not be appropriate if there is no party who is actually speaking for the patient, or if the person speaking for the patient is intimidated by the other parties. Safeguards in the mediation context would logically include elements of due process, particularly notice of the mediation session, information about mediation and participating parties' rights, a neutral mediator or mediators, and assurance that the voice of the patient is being "heard."

The difficulties in determining standards for the internal workings of the ethics committee under an adjudicative model apply to a mediation model as well. At a minimum, we would want to know whether all relevant parties were present and had an opportunity to express their interests and position. We can also ask whether the facilitators were, in fact, neutral and not biased or heavy handed: did they provide information on relevant ethical principles and law, and did they let the parties reach their own agreement or did they impose a decision on them? In addition, we will want to know how these factors affected the ultimate outcome of the case.

Whether a consultative, adjudicatory, or mediation model is selected, one component of an evaluation of *process* will be to ask the patient or family member who sought the committee's assistance for his or her evaluation of the committee's process. Types of questions might include the following:

- Were the individuals who responded to the request for services sensitive to the concerns of the consulting patient or family members?
- Did the consult team ask useful questions, clarify issues, and seem knowledgeable?

- Did the consult clarify ethical issues versus other concerns?
- Did the patient or family member become aware of additional points of view and gain confidence in his or her decision making?
- Did the committee process help family members to determine what the patient would have wanted?

A questionnaire might also include more practical questions about promptness of the committee response and ease of contacting the consult team.

Although I would argue that these criteria are important measures of committee process, requiring them as the standard for evaluating ethics committees calls for additional empirical study of how these process measures in fact relate to outcomes.

Outcome

An evaluation of outcome may also include both subjective and objective measures. Some have relied exclusively on subjective measures. For example, La Puma et al. (1992) relied solely on the perceptions of physician users in analyzing the effectiveness of an ethics consultant. From the perspective of protecting patient interests, however, it would be most important to ask the patients or their surrogate whether they were satisfied with the outcomes. In many cases, the patient will lack decision-making capacity. Evaluators can then ask the patient's family members or surrogates who participated in the consultation whether they were satisfied with the committee recommendation.

Although assessing user satisfaction is important, relying on subjective measures alone is insufficient. As Tulskey and Lo (1992) argued in a critique of La Puma's study, in addition to data on user satisfaction it would be helpful "to evaluate . . . objective measures of dilemma resolution." The difficulty comes in determining what those objective criteria should be. If there is any evidence of the patient's wishes, evaluators will want to compare that to the final outcome. However, if there is no such evidence, the appropriate criteria for evaluation, if any, are controversial.

When there is no evidence of patient wishes, evaluators must determine whether a committee's recommendation was in the patient's best interest. This is the appropriate standard from both a legal and ethical perspective. Given the epistemological problems inherent in knowing what is best for a patient who is unconscious or incompetent to make his

or her own medical decisions, however, there is reason to doubt the capacity of any reviewers to be sure of the correctness of a given decision. As some philosophers have pointed out, in many cases either terminating or continuing life support for a patient will be ethically appropriate. As a result, we cannot and should not expect ethics committees to come up with a “best answer,” only one that is ethically and socially acceptable. To determine whether the recommendation was within the bounds of what is ethically or socially acceptable, we would have to resort to review of the recommendation by a trained bioethicist (for ethical “rightness”) or by a panel of citizens thought to have values similar to those of the patient, who, much like a jury, would determine whether the recommendation was socially appropriate.

Finally, evaluators must try to assure that ethics committee recommendations are being applied consistently and without bias. Therefore, from a policy perspective, evaluators will want to ensure that there is no statistically significant difference in ethics committee recommendations for certain vulnerable groups, or for groups that have been traditionally disadvantaged: minorities, women, the poor, the homeless, or individuals without family members. A discovery that committees in the aggregate were treating these groups differently from others—terminating their life supports more frequently or overtreating them more often—would raise troubling questions about the fairness of ethics committee recommendations.

Again, in considering outcome, it is important to look not only at the ethics committee’s recommendation, but also at the ultimate patient outcome, and to consider whether it was consistent with the committee’s recommendation. Committees whose recommendations are not followed will have little impact on protecting patients’ interests.

Cost Effectiveness

The costs of case consultation by ethics committees will probably fall on three groups: the individual committee participants, those who use the committee (both health care providers and patients and their families), and the institution that the committee serves. From the perspective of the committee members who are not hospital employees, the costs to them of being on the committee will be their opportunity costs. For most physicians, the costs will comprise income (in kind or in cash) they

would receive through alternative uses of their time (i.e., seeing patients, consulting, or teaching).

The hospital administration will incur such direct costs as those for providing staff support and education programs for committee members, including speakers, videos, written materials, and conference attendance; the hospital will also assume the indirect costs of finding other employees to fill in for committee members while they are engaged in case consultation activities. For example, it may be necessary to find another nurse to replace one who is attending a case consultation meeting, especially if she cares for patients directly. If she is an administrative nurse, attendance at these meetings may be part of her job. Meetings held when a nurse member is not "on duty" will cost the institution nothing and will figure as opportunity costs to the nurse.

The cost to users of the committee should also be considered. Physicians, who are the predominant users of these committees, encounter costs that are similar to those of physician members: their opportunity costs, defined as what else they could be doing during the time they are consulting with the ethics committee.

The costs to family members who use the committee must also be counted. These will include any direct or indirect costs they may incur, such as taking time off from work, traveling to the hospital (from in or out of town), hiring a babysitter, as well as their opportunity costs.

Also significant to families will be their emotional costs. One shortcoming of cost-effectiveness analysis, however, is that it may not adequately account for these types of costs. Yet, when compared with some alternatives, such as the courts, on the measure of emotional price ethics committees may be much less costly.

The costs of hospital ethics committees appear to fall primarily on individual members and users who are not hospital employees. The costs to hospitals themselves are relatively low. I mentioned earlier that although there is currently no governmental funding of ethics committees, if public funding were to be considered, the level of funding at issue would be balanced against the effectiveness of the committee and compared with the costs of alternative programs that might achieve the same results.

The real challenge in applying cost-effectiveness analysis to ethics committees, however, lies in determining the appropriate units of effectiveness by which to assess them. Although I have discussed the difficulty of setting outcome standards for measuring the quality of ethics

committees, I will try here to suggest concrete measures of effectiveness. If our purpose is to protect patients' interests, cost effectiveness might be measured by researching a year's worth of cases considered by a hospital ethics committee and asking these questions:

1. What percentage of case decisions were consistent with the patient's preferences or the patient's best interest?
2. In what percentage of cases were surrogates satisfied with the process used and/or the recommendation made?
3. What was the cost to all of the relevant parties for bringing all these cases to the committee?

In order to conduct an actual cost-effectiveness analysis, each of these questions should also be asked regarding alternative mechanisms for dealing with these cases. Among these might be bringing the cases to a single bioethics consultant, to the hospital chaplain, or to a member of the clergy; going to court; or adhering to the status quo, that is, dealing on a "catch-as-catch-can" basis with individual health care providers. Two outcomes for each alternative would be obtained. One outcome would be a result of patient-based measures, that is, patient preferences and patient interests; the other, a result of surrogate satisfaction. We might find that ethics committees are more cost effective than the alternatives on neither, one, or both criteria.

Conclusion

The time has arrived for serious and formal evaluation of ethics committees. The old excuses—that the committees are in their infancy and that more time is needed to experiment with different approaches are no longer valid (see Wolf 1991). It is time to assess the experimentation results. Public policy makers cannot continue to push legislation mandating or advocating the establishment of these committees without examining them more critically. The limited data available raise concerns about the performance of ethics committees, at least from the perspective that their purpose is to protect patients' interests. In large part, these concerns can be attributed to the committees' lack of clear purpose or to their multiple and conflicting goals. In their desire to persuade health

care providers to use them, some ethics committees seem to soften their "patient advocacy position," adopting instead a more objective stance that balances the interests of all relevant parties, including the institution. Due process provisions have not been implemented in many cases because committees do not necessarily see patient interests as their primary responsibility; they continue to function informally, using the ad hoc medical consultation process most committee members, as health care professionals, are comfortable with.

Yet, based on the scanty data available, committees cannot be condemned. Although they might not meet the public policy goal of protecting patient interests sufficiently to warrant legislation mandating their establishment or encouraging their use, they may be filling an important role from the perspective of health care institutions. We must conduct more research and gather more data before arriving at any generalizable conclusions. In this article I have sought to assist public officials and policy makers who wish to evaluate ethics committees by providing a framework and suggesting criteria for evaluation. I have also attempted to apply the criteria and to point out the conceptual and practical limitations of certain measures. Access is perhaps the "clearest" and most easily measurable of the evaluation criteria, yet empirical data on access are deficient. Quality must be considered, but certain aspects of quality will be nearly impossible to measure. Structure seems to be the simplest measure of quality for an ethics committee, just as it is for measuring the quality of health care. Yet, more empirical studies are necessary to determine what types of structural standards produce good process and outcomes. Process can be broken down into types of measures based on due process and those stemming from the internal deliberations of the committee. We need more work on what these measures should be, but I have set forth some minimal process criteria. In measuring outcome, user satisfaction and consistency with patient preference are appropriate for some decisions. Other outcome measures remain elusive, especially for the application of a best interest test.

We also need to begin to assess processes and outcomes of ethics committees and the relation between the two. Research on the dynamics of ethics committees and their recommendations will be a great service to the health care community.

Finally, cost effectiveness is both a valid and an important criterion for evaluating ethics committee performance. Some effort to assess the costs and benefits of these committees, compared with the other relevant

alternatives for dealing with ethical dilemmas and patient provider conflict, is warranted.

As the President's Commission pointed out in its 1982 report on making health care decisions, "Very little is known . . . about the actual effectiveness of institutional ethics committees, especially in comparison with private, informal mechanisms or with judicial decision-making for patients lacking decision-making capacity" (187). The comment is still relevant over a decade later. Some efforts on this front are sorely needed.

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